

HIV & AIDS INFORMATION SUMMIT

March 19, 2003

Defining common challenges and identifying potential strategies to improve the coordination and electronic dissemination of accurate and current HIV information.

Welcome

Information is crucial...

we need efficient and effective ways of disseminating INFORMATION

Elaine Graham

HIV INFORMATION on the INTERNET

EXTERNAL factors

Who will be using the INFORMATION?

Many groups overlap

Focus on a smaller segment
- less duplication
- concentration



Are restrictions consistent with project goals?

APPROPRIATE? FORBIDDEN?

Find alternatives... **BE CREATIVE!!**

dated updatable
CD-ROM
Websites on a CD-ROM

Internet band with concentrated between US and EUROPE
- all the right people able to access it?
-> MORE PCs than INTERNET ACCESS!!

Partners? or Competitors? LINKING! ACCESS!
Both... and it makes for good collaborations!

INSTITUTIONAL factors

Is it a means or an end? Do you have the resources to
- MAINTAIN IT
- EVALUATE IT

Disclosure content? Is it C.V. worthy?

Where are you on GOOGLE?

Larry Pieper

How does this information SERVE?

DELIVERABLES

- ✓ Is it credible, relevant, current?
 - ✓ Is it accurate and complete?
 - ✓ Are limitations disclosed?
 - ✓ Are links evaluated, logical, navigable?
 - ✓ Designed well?
 - ✓ Is its purpose clear?
 - ✓ Are copyrights clear and permitted?
 - ✓ How is the down load time?
 - ✓ Do people feel safe using the site?
- CONFIDENTIALITY ISSUES

KEYNOTE SPEAKERS

Presented by:

- The Pacific Southwest Regional Medical Library
- NN/LM
- California AIDS Clearinghouse

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- UCLA Biomedical Library

HIV Related Anonymous SEX v.s. Sex within relationships: IS THERE A DIFFERENCE?

- We can't say enough to ANYONE about AIDS prevention!!
- Is funding reaching the right groups?
- What is the context of SEX?

IN THE EARLY 80's

gay men
IV drug users
Sex workers

Condom use
Reduce sexual partners
Reduce drug use

Heterosexual relationships of 4 years or more have no RISK

IN THE 1990s

Rates of married women rose
Male/female transmission 12x that of female > male

The sexual model has been based on ANONYMOUS SEXUAL CONTACT

99% of interventions involve individuals

Who are you having sex with?

IT'S INTERACTIVE!!

We need to let people BE who they need to BE

Who makes decisions about condom use?

POWER IMBALANCE

Religious/Cultural CONSTRAINTS

- skin to skin
- sex for reproduction
- body fluid exchange
- Non-condom use
- Dislike of masturbation

The internet is a great opportunity for people to get into anonymously but it is not used in procreative ways

We need to learn/teach these skills

NOT SOCIALIZED TO COMMUNICATE VERBALLY ABOUT SEX

How do we get information into where people go?
CHURCH
SCHOOL
SPORTS
EVERYWHERE!!

Normalize sex education

EXPECTATIONS HISTORY

We rarely ask:

- IF THERE WAS CHILD SEXUAL ABUSE
- If they identify as heterosexual, if there are same sex relations also

multiple partners
non condom use

You need to know

WHO ARE YOU?
WHO DO YOU DO?

Look at behavior first
RISK REDUCTION
HARM REDUCTION

THERE IS CONTEXT TO SEX

TABOO

SECRET

RISK-TAKING

UNKNOWN

IMMEDIATE GRATIFICATION w/o INTERPERSONAL

COMPULSIVE

How do you live with the reality that sex (and love) can cause death?

Challenge yourselves to get out of the box

- ask new questions
- think differently
- look through new eyes!!

BE CHALLENGING!!

SEX in relationships

CONNECTEDNESS

Prove LOVE and TRUST

GENDER

- To keep partner
- Prove love
- Have children
- Why they have sex

"THE" OFFICE

EXTERNALIZED CONTROL "Blame"

- Plan for it
- Take responsibility for it

GROUP SEX
S+M experiences often are knowledgeable

No More Clueless SEX.
10 Sexual Secrets that work for BOTH of YOU.

by Gail Wyatt and Lewis Wright MD

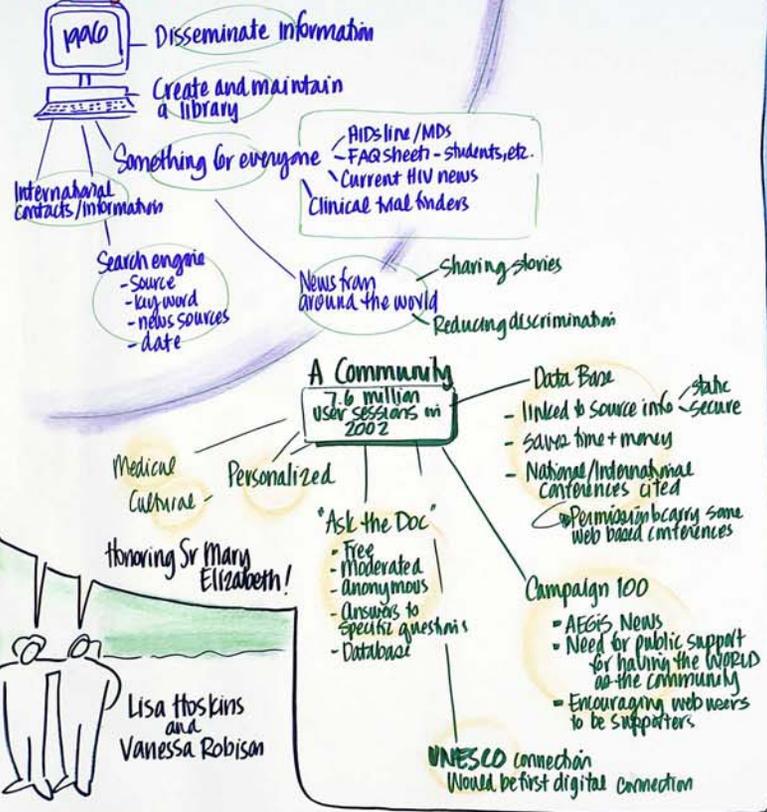
CULTURAL CONTEXTS



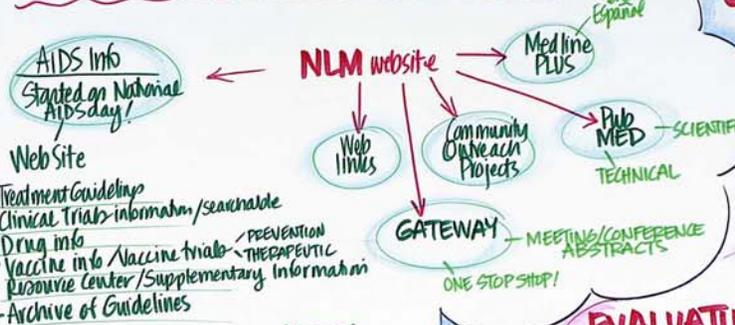
Gail Wyatt

AEGIS "A GATEWAY"

www.aegis.org



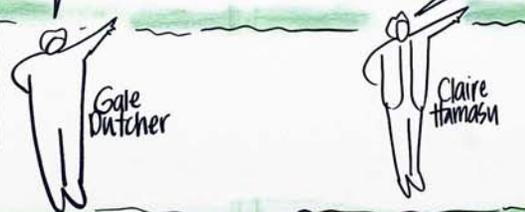
HIV/AIDS INFORMATION Resources from the National Library of Medicine



A Government Resource LINKING to Government and other resources

- Strict guidelines for selecting core resources

Daily use is increasing even though it is quite new



EVALUATING HIV/AIDS INTERNET RESOURCES

- Who are they promoting?
- What claims are they making?
- Who are they associated with?

- Quality, Disclosure, Authority**
 - How is information vetted?
 - How are resources cited?
 - Is it linked to official/sound websites?
 - Is source established, respected, dependable?
 - Is advisory board named?
 - Diagrams?
 - Unique information?

- Source credibility, Attribution**
 - Contracts?
 - Purpose?
 - Funding?
 - Who are they?
 - Is it clear?

- Be a cyberskeptic! Evidence, justifiability**
 - Research vs opinion?
 - Dated / latest?
 - Are ads clearly labeled?
 - Contact info?

- Privacy Disclosure**
 - What info are they collecting? Demographic or personal?
 - Are they selling the info to another source?
 - Is there a privacy policy?

PANEL PRESENTATIONS

MAXIMIZING VISIBILITY of your WEBSITE

Planning

- * Why?
 - * Who?
 - * How do they find you now?
 - Server logs?
 - REFERRER
 - \ Bookmarks are BEST!!
 - \ SEARCH ENGINE
 - look at search terms
 - * Are you in search engines now?
 - How do you look? PAGE RANK
 - Backward links?
 - How many pages on your site show up?
 - * Look at your competition
 - Look at their key words/html
- Build your list of keywords

Design for findability

- Build your list of keywords
Site pages
Common
- ▶ Use html properly
 - ▶ Think about structure
 - ▶ Create a good experience for the user
 - ▶ Good title
 - ▶ No gratuitous html
 - ▶ Use meta data / meta tags
 - Use your description
 - Keywords
 - Robots
 - ▶ Create gateway / doorway / page
 - ▶ Talk to a consultant

- AVOID
- Competitor names
 - duplicate keywords
 - tiny / invisible text

PROMOTING YOUR SITE:

- #1 Lots of links
 - to highly ranked sites
 - reciprocal
- #2 Submit your site
 - YAHOO
 - Submit by hand
 - Pay for INKTON for another me
 - Keep records of submissions
 - Assign it to a student as a summer project
- #3 Announce your site
 - List serv
 - Put url on everything

Look at
www.searchenginewatch.com

Jenny
Reiswig

INFORMATION ACCESS and DELIVERY

- ▶ Familiarize yourself with your local library that can provide you with services
 - Lonesome Doc
 - Use from within Pubmed

We at the
Pacific Southwest Regional
Medical Library are here
to help you

Julie
Kwan



PURPOSE

To define common challenges and identify potential strategies to improve the coordination and electronic dissemination of accurate and current HIV information.

Brainstorming

- Do not judge ideas ~~GOOD~~ ~~BAD~~
- Repeat ideas are fine
- "Piggybacking" off someone else's idea is fine
- Wait for silences to the end...
The greatest creativity often follows.
- The more ideas the better!

TOPIC: HOW TO COPE WITH INFO OVERLOAD

RECOMMENDED NEXT STEPS

Knowledge about better, more efficient ways to access resources.

Take time out - important!

You and your clientele need filtered / prioritized info.
(folders, favorites, binder organized by area)

Use judgement as info. intermediary - overload vs. useful user friendly info.

Knowing how much is enough to disseminate

BRILLIANT INSIGHTS



WHO MIGHT CARRY THEM OUT

TOPIC: HOW TO DISSEMINATE + SELECT INFO SOURCES WITH THE RIGHT MESSAGE

RECOMMENDED NEXT STEPS:



BRILLIANT INSIGHTS:

? What is "right" info?
All these are part of a process



WHO MIGHT CARRY THEM OUT

TOPIC How To Develop Electronic SAFER SEX MESSAGES.

RECOMMENDED NEXT STEPS

Create procedures to confront/^{combat} medium that promotes unsafe behaviors.

Increase awareness of electronic media; variability and new/customized ways it is used.

Holistic health/
Sexual health

Identify populations involved
- needs
- customize

Training (web-based) /
tool boxes

BRILLIANT INSIGHTS



WHO MIGHT CARRY THEM OUT

TOPIC: _____

RECOMMENDED NEXT STEPS

Include anecdotal user information on HIV/AIDS websites (e.g. Amazon comments on books.)

Conduct a needs assessment for the intended audience of an HIV/AIDS website.

Create archiving mechanisms so important information does not disappear.

Eliminate the myth of the Internet being able to easily provide all the answers.

Take a systems approach... workflow to posting information on the web - it is not just a dumping site with rotting information.

BRILLIANT INSIGHTS



WHO MIGHT CARRY THEM OUT

TOPIC: _____

RECOMMENDED NEXT STEPS:

Sliding fees for ILL services to "poor" info. providers

Clarify COPYRIGHT LAWS

Expand electronic license access to HIV/AIDS info. providers in Calif.

Provide better access to abstracts / full text on behavior change, psychology

BRILLIANT INSIGHTS:



WHO MIGHT CARRY THEM OUT

TOPIC: _____

RECOMMENDED NEXT STEPS

Sponsor a meeting of AIDS/HIV electronic information providers to discuss topics like collaboration, standards, etc.

NLM sponsored working group to describe the important characteristics of the contents of HIV/AIDS websites and conduct a pilot project to test the concept.

Issue an RFP to conduct an evaluation of HIV/AIDS information websites.

Conduct a study on what people do with the information they obtain on HIV/AIDS websites.

Market HIV/AIDS info websites to librarians. Train librarians to better provide access to HIV/AIDS info on the Internet.

BRILLIANT INSIGHTS



WHO MIGHT CARRY THEM OUT

TOPIC: Identify CURRENT ACCURATE & INACCURATE HIV INFO

RECOMMENDED NEXT STEPS

STATS II

- Compiling & identifying data
- Identifying availability of local data

STATS

- Disclose data limits
- Emphasize trends not numbers
- Make Statistics REAL & understandable

BRILLIANT INSIGHTS

Safeguarding

- Vulnerable information

Health literacy-education

- improving education K-12
- funding peer advocates
- train the trainer



WHO MIGHT CARRY THEM OUT
Government - all levels
CBO's ; Libraries

TOPIC: ELECTRONIC SAFE SEX MESSAGES

RECOMMENDED NEXT STEPS:

HOW TO REACH THEM
• Chat Rooms, BBS

MESSAGES
Appropriate, not same for
each group

Influencing
Community
Norms

NEED: Assessment
for TARGETED Pops.
• highly involved surveys
• flyers

BRILLIANT
INSIGHTS:



WHO MIGHT CARRY THEM OUT
CBOs ; NGOs ;
PHD (health dept.) ; outreach
workers

TOPIC: Sharing Strategies & Networking to Provide Accurate Info

RECOMMENDED NEXT STEPS

SPEC. POPS II

- Involve targeted pops. in developing information
- E-bay interface for data providers

SPECIFIC POPULATIONS

- Targeting Info/
Tailoring Info.
- Coordination of info GAPS
- Availability of camera-ready materials for distribution

**BRILLIANT
INSIGHTS:**



WHO MIGHT CARRY THEM OUT
Libraries; CBOs; HIV/AIDS
website manager.

TOPIC: Who are we reaching? How are we doing?

RECOMMENDED NEXT STEPS:

- ① Be clear on who we are trying to reach? what we are trying to do
- ② Evaluate what our web site needs - Also what our intended audience needs
- ③ Think about the medium or intermediate messenger - web may not work for all
- ④ Web site should have easy to find links to client resources - culturally competent translations, etc.
- ⑤ Conduct evaluation to determine best practices & improve system

BRILLIANT INSIGHTS:

Send van & mobile PC into hard to serve populations - do test of this

Offer incentives to access the net

Address gov't restrictions - guts (bl aware) at all levels



WHO MIGHT CARRY THEM OUT
NLM (5)
Advisory boards (1) (2) (3)

BREAK OUT GROUP REPORTS (PROCESS NOTES)

● **CHALLENGE:** How to combat (in structured ways) messages that do NOT promote safe behaviors

● **CHALLENGE:** Use what is already working... embrace **SHARING** of INFORMATION

● It was very personal... It's all about US!

Don't forget... **TAKE TIME OUT** from everything!

● **REMEMBER** What you put out (on to the internet) is the BEST that you can do.

● **CHALLENGE** Writing in the users language is better than translating

● **REMEMBER** Collaborations will help create cultural accuracy

● Anecdotal information
I found this really helpful...
I liked this

Think in **SYSTEMS**

Build what you DO into the way you work

Clarify and understand copyright LAWS.

What do people do with the information once they turn off the computer?

● Most of it came down to Statistics.... but is it the last word?
Make them relevant!!

● Does your city or county have relevant HIV/AIDS information?

● Is anyone looking for what is MISSING?

● Create an e-bay type interface to find information that you need

HIGHLY EVOLVED SAVAGES!

We were a very diverse group

The basic audience we need was a generic audience.



Send Mobile PCs into hard to reach populations
BREAK THROUGH IDEAS
Coupons on the net

Medline Plus needs tutorial
LATER
Do hard to reach populations use the internet?

We could have used 3 more days...

AND IN CLOSING...

★ You are the ones who make this happen

Thank you for being a part of this

★ Thanks for all the detailed planning

★ Thank you for the **SPONSORSHIP!**

* It's hard to reach and easy to overload rural populations

* Be aware of **NEW** technologies and access to your site

Go and do the work that you do!!

Comments from the whole group

